

Nebraska Strives To Care For Ventilator-Dependent Children At Home

by Dale Ebers, MD

As a medical director of Services for Crippled Children in Nebraska, I would like to educate you as to what services are available. Maybe this will give us a springboard as to what other things can be accomplished nationwide.

Crippled Children's programs in Nebraska were expanded a great deal under the governorship of J.J. Exon, who is now a senator. He and his wife were very, very interested in chronically disabled children, and through his efforts, our budget was increased considerably and a lot of categories were included in our program which were not in the program before.

We have a unique position in Nebraska where all children who are provided any care under 94142 are coordinated through Services for Crippled Children. So, every child who is disabled in the state of Nebraska has a record in my office, whether they are eligible financially for aid from Crippled Children's or not. We are basically

constituted to provide help for the medically indigent family — not the indigent family. The medical costs of some of these diseases and conditions can be horrendous — you can run through thousands of dollars so fast you can't believe it. If the family or patient is Medicaid eligible, we ask Medicaid people to do the financing, and we do the case management. In that way, we have more uniform control over the quality of care that is delivered, regardless of where that delivery is made in the state.

We hold the basic premise that all children should be cared for at home, or as close to home as possible. That is probably a personal bias that I hope is reinforced in the state.

We have enlarged the area of hyperalimentation. Hyperalimentation means there is a permanent central line into the cardiovascular system, which creates a great possibility of infection. Eighty percent of the kids who are on a program for hyperalimentation have a short

bowel syndrome or intractable diarrhea and are usually between 6 and 18 months of age. Dr. Vanderhoff, who trained at UCLA and came back to Nebraska and wanted to get into this, came to me and asked if Crippled Children's could support this program in the hospital. We discussed the problem and decided we would have to find a way to do treatment at home. Vanderhoff has accomplished this. He developed protocol and he has a nurse who spends about a week teaching parents how to prepare the solutions for treatment. She then supports them at home by visiting or calling once a day for the first few weeks, and then visits once a week. Vanderhoff usually sees them once a month. The program's been going on for about three years now, and this past year it cost \$100,000. If you would have had those kids in the hospital, we would have been spending in the range of half a million dollars. Obviously, that is a very cost effective procedure. ●